How can social media lead to co-production (co-delivery) of new services for elderly population? A qualitative study

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Contribution

HD and SA conceived this work. HD collected data for this study. HD led on data analysis and drafting of the manuscript. All authors (HD, SA, HM, RW) have commented on various versions of this manuscript and inputted into the analysis.

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Abstract

Background: The future of health care services in the EU faces the triple challenges of ageing, fiscal restriction and inclusion. Co-production offers ways to manage informal care resources to help them cater for the growing needs of elderly people. Social media (SM) is seen as critical enabler for co-production.
Objective: We investigate how SM - private Facebook groups, forums, Twitter, and blogging - acts as an enabler of co-production in health and care by facilitating its underlying four principles: equality, diversity, accessibility, and reciprocity.
Methods: We used Normalization Process Theory (NPT) as our theoretical framework to design this study. We conducted a qualitative study and collected data through 20 semi-structured interviews and observation of the activities of ten online groups and individuals. We then used thematic analysis, and drew on principles of co-production (equality, diversity, accessibility, and reciprocity) as a deductive coding framework, to analyse our findings.
Results: Our findings point to distinct patterns of feature use by different people involved in care of elderly people. This diversity makes possible the principles of co-production by offering equality amongst users, enabling diversity of use, making experiences accessible and encouraging reciprocity in the sharing of knowledge and mutual support. We also identify that explication of common resources may lead to new forms of competition and conflicts. These conflicts require better management to enhance the coordination of the common pool of resources.
Conclusions: SM uses afford new forms of organising and collective engagement between patients, carers and professionals, which lead to change in health and care communication and coordination.

Keywords: Social Media, Co-production, e-health, Co-service, Social Networking, Web 2.0, Health Informatics.

Introduction

Health and care in the EU faces the triple challenge of ageing, fiscal restriction and inclusion [1]. In the UK, the number of elderly people will increase to 6.6 million over the next 25 years. In Scotland, by 2035 the 65+ years group is projected to have grown by 82%. This study focuses on three important problems related to the aging population in Scotland, and the wider UK. The problems are: 1) Population increase of elderly people; 2) Insufficient resources to meet the health and care needs of the elderly population; 3) Social Exclusion of the elderly. These lead to increased need for government expenditure to provide and deliver health and care services, increased need for expenditure by elderly people while their income is static or falling.

The statistics show the needs of elderly people are growing and there is an increased requirement for carers [1]. Currently the population of informal carers is more than 10% of the 65M population of the UK. It is projected that this number will increase to 9 million of 73.2M (around 12% of population) in the next 25 years. The current value of care is worth an estimated £132bn per year – approximately equal to the total annual cost of health spending in the UK, which was 134.1bn in year 2014-15[2]. So an important challenge is how to resource care and health of elderly people in the future. Depending solely on economic growth to fulfil the finance needs of public services is unlikely to meet the need in a time of austerity and will inevitably lead to poorer quality of service and outcomes. Hence new ways of meeting the need for health and care are needed [3]. In order to reshape service delivery, we need to consider how to utilize diverse resources.

The Health and Care system in the UK and Scotland is being reformed. The Scottish government has announced the need for better coordination and integration in this process [4]. Examining the concept of co-production is an initial step in reforming the service delivery. Boyle and Harris from the New Economics Foundation (NEF) give a definition for co-production:

"Co-production means delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbors. Where activities are co-produced in this way, both services and neighborhoods become far more effective agents of change." [3]

There are a range of perspectives on the production and use of health and care services. A critical aspect of such services is the governance of their production and use. In this context one strong standpoint sees health and care resources as 'common pool resources' [5]. Common pool resources (CPR) refer to:

"a system that is sufficiently large as to make it costly (but not impossible) to exclude potential beneficiaries from obtaining benefits from its use. To understand the processes of organizing and governing CPR, it is essential to distinguish between the resource system and the flow of resource units produced by the system, while still recognizing the dependence of the one on the other." [5]

This common pool of resources may involve patients, informal carers, social carers, volunteers, professional carers(caregivers), and health professionals who can be seen as co-producers of health and care services. In this paper, we focus on informal carers, volunteers and patients, and examine how this large pool of informal carers and patients could, with more careful utilization, further augment the effort devoted to care in the UK. Current public services are poorly equipped to exploit the potential social economy of family and neighbors.

The full participation of informal carers in the co-production of health and care has the potential to play a significant role in the sustainability of health and care delivery. A

pressing issue is how to coordinate this massive resource with the formal health and care system to enable true co-production of health and care. This massive resource is spatially dislocated and temporally uncoordinated and engaged in responding to very local demands. Modern information and communication technology (ICT) is seen as a key enabler to overcoming such obstacles.

Increasingly e-health and care is seen as the tool to re-shape healthcare systems [6]. We propose that, in particular, SM can be viewed as an enabler for co-production. Communication is a key element in co-production that enables coordinating across various boundaries. SM cuts across boundaries, its use is well understood, but its effects are much more poorly understood. Therefore, this paper focuses on how SM enables this co-ordination.

In order to explore the role of SM in the context of co-production (with carers, patients and volunteers in focus) we use Cahn's framework as our analytical lens, Cahn [7] identifies the following principles as the elements that put co-production into action: equality, diversity, accessibility and reciprocity.

Equality –no group or individual is more important than others. Everyone is equal and they have assets to contribute to the whole.

Diversity –diversity and inclusion are important principles in co-production. So, diverse groups must be included.

Accessibility - if everyone is going to take part on an equal basis then everyone needs to have the same opportunity to be involved activities, in a way that is suitable for them.

Reciprocity – When people put in effort to contribute they need to feel valued as well as needing to receive something back. This means that everyone is responsible and they have expectations, and therefore it is a mutual process.

Whilst these are critical elements of co-production, achieving all of them at the same time may result in asymmetry (amongst the elements) or conflicting goals. For instance, in some cases encouraging inclusivity and diversity (having a large number and more diverse actors involved in one space) may be at the cost of equality and reciprocity (not everyone contributes equally or at all times). Therefore, in this paper, we initially highlight how SM enables these four elements, and then we discuss the possible conflicts.

By using this framework, we foreground the communication aspects of SM. We recognise this as one of the numerous aspects of co-production. In particular, further research is needed to explicitly heed to issues of resourcing, conflict and competition for resources, and the overall governance of health and care provision. Our focus here, therefore, is on the communication and cooperative utilization of health and care resources amongst patient representatives, carers, and volunteers. We will therefore discuss its limitations in the discussion section, and address the broader aspects and possible contentions involving health professionals and social workers, in a later paper.

SM are online tools for the creation and sharing of digital content. They aim for widespread use and are capable of supporting an unlimited number of users. Kaplan and Haenlein [8] defined SM as "a group of Internet-based applications that build on the ideological and technological foundations of Web 2.0, and that allow the creation and exchange of user generated content". Dissemination of content operates at Internet speeds. It has been argued that SM have caused a change in social action in many areas [9, 10]. SM increases social interaction between patients and health organisations. Moorhead, Hazlett [11] explain that SM is a powerful tool for collaboration between users and it acts as a social interaction mechanism for its wide range of professional and non-professional users. It empowers public and patients by enabling them to

communicate with each other and exchange health information [9, 10, 12]. It enables users to discuss sensitive issues [13, 14]. Moorhead et al conducted a systematic review of uses of SM for health and shows that SM offers peer, social, and emotional support for its users. They also demonstrate that SM increases interactions for patients, their families and friends.

The term was coined by Shipley after his research and reports on technology trends [15]. SM have since become media for the creation and maintenance of connection and interaction amongst individuals [16, 17]. They are currently used widely by diverse range of users and have become amongst the largest number of most visited sites worldwide [18].

Several studies [8, 19, 20] categorise SM into eight groups:1- Wikis, 2- Blogging 3-Micro-blogging, 4-Content communities, 5-Instant messenger and forum, 6. Social network sites, 7- Mobile SM and 8- Virtual World and Online Social Gaming

In health and care, we divided SM to three groups: A) SM that were created for general purpose use and are now used for health and care e.g. Facebook Groups (FBG). B) SM that were created for health purposes and make use of generic SM for other purposes (e.g. 3D-Doctor or some other health applications that make use of Skype to connect patients to the doctors), and finally C) applications created for health and care purposes that use the concept of SM (Health SM) e.g. healthunlocked.com is new SM for health purposes [21].

Aim

Our study investigates the current and possible future for SM as an enabler of co-production in health and care for elderly people. To achieve these aims two main sets of questions are asked: what are the current uses of SM in health and social care? How can SM be reshaped to enable (and reshape) health and care co-production?

We consider a typology of opportunities and limitations of SM for health and care. Table 1 shows existing health and care service bundles with (1) existing or (2) new SM tools (new SM means some application developed for health and care that used the concept of SM like Healthunlocked). New health and care service bundles with (3) existing or (4) emerging SM tools. In this part of the research we focused on (2): "How current SM help to reshape or change health and care services". In other words, we assessed how existing SM acts as an intervention during the reshaping of health and social care in the UK by enabling co-production (in particular co-services).

Table 1- SM and Health and Care

		Health and Care	
		Current Service	Change Services
Social Media	Current App.	Use of current SM in existing situation (1)	**Current SM help to change health and care service (2)**
	Redesign	New SM to cater for the current health and care services (3)	New SM with New Health and Care Services (4)

Methodology

Overall Project

This paper focuses on one of the four aspects of a larger qualitative study which investigates the sociotechnical aspects of the current and possible future uses of SM by different organizations and groups of health and social care as an enabler of co-production in the UK, in particular Scotland. We conducted 20 semi-structured interviews which focused on the services offered, the types of online applications (particularly SM) used, their challenges and the future possibilities of SM. We used purposeful sampling to select organizations and groups who were providing care services to elderly people. We used a combination of interviews and analysis of the activities and content of online groups to collect data. Combining different methods enabled us to triangulate the data sources to validate our findings.

Material and Methods

This paper focuses on the second section (2); how current SM help to change health and care service (Table 1). Our appraisal adopts a socio-technical technique, [22, 23] using a mixed methods framework including multiple methods (interviews, observations of online activities, and secondary data analysis) and multiple sources of data. Table 2 summarises the data collection methods and sources. For the purposes of anonymity, names have been replaced with pseudonyms.

Table 2- Summery of primary data collection

#	Name	Description	Interview	Observation of Online Activities			
				Twitter	FB	Website	Others
1	Organization 1	Professional Sector	X	X	X	X (Web 1.0)	
2	Organization 2	Intermediary	X	X	X	X (Web 1.5)	Blogs
3	Organization 3	Intermediary	X	X	X	X (Web 1.0)	LinkedIn, Instagram, YouTube
4	Organization 4	Intermediary, Part of a larger project	X	X	X	X (Web 1.0)	YouTube
5	Organization 5	Intermediary, Part of a larger project	X	X		X (Web 1.5, Web 2.0)	Blog
6	Alison Morgan	Project Manager (FB Group admin)	X				
7	Sarah	Patient (Forum and FB Group user)	X				
8	Edmund	Patient (Forum, FB Group, YouTube, and video blog user)	X				
9	Carole	Patient (forum, FB Group, and charity website user)	X				
10	Donna	Patient and carer (Forum, FB Group, and voluntary organisation website user)	X				
11	Karen	Carer (forum and FB Group user)	X				
12	Laura	Patient and carer (Forum and FB Group user)	X				

Theoretical Framework

NPT has been used as our theoretical framework to enables us to obtain meaningful understanding of the complex socio-technical processes involved in use SM tools and service within health and care co-production. NPT offers a whole system perspective, to assist researchers to make sense of the social and organizational aspects of different interventions, and helps us to better conceptualize our complex adaptive systems. NPT, which has been used in many e-health research studies, has been used as a tool in this research to assess the changes brought about by the introduction of SM into the personal and organizational lives of patients, carers, and organizations involved in care activities. (Table 3)

Table 3- Representation of the 4 constituent NPT constructs which attend to the 4 key aspects in e-health implementation [22].

	Coherence (sense-making work)	Cognitive participation (engagement/buy in work)	Collective action (enacting work)	Reflexive Monitoring (appraisal work)
Questions	What gets done with SM in co-production? What gets done with other mechanisms?	How does SM facilitate participation within the intervention?	If an actor did not have SM what would happen to their work? (in terms of quality of service delivery)	Does SM allow participants to reflect on the work they have done?

Data Collection and Qualitative Data Analysis Procedure

We conducted twenty interviews (approx. twenty-two hours) with patients, carers and employees of third sector or intermediary organisations (i.e. charities) which provide funds and services for developing programmes to reshape of health and care services in Scotland, and companies or organisations working in the health sector providing services to elderly patients with long-term conditions.

We used purposive sampling to select the interviewees. Our purposeful sampling strategy aimed to identify organisations that actively used some type of SM in their activities. The selection criteria for organisational participants was people who were either involved in providing carer activities, decision makers, or those involved in design of ICT programmes for elderly care. For non-organisational participants, we aimed to select interviewees who were either patients or carers who actively used some type of SM in their day-to-day life.

We used the NPT framework to develop an open-ended interview question guide (Table 4). The interview questions were tailored to the roles of individuals and further refined throughout the research based on the findings of prior interviews.

To complement this data, we used secondary data, generated by one of the above-mentioned organisations, about uses of SM in self-management. The data consisted of eight interviews with people with long-term conditions who used SM for health purposes. Data from these interviews were analysed together with the primary interview data.

Finally, we observed the online activities of interview participants (organisational participants) and their uses of SM for health purposes. This enabled us to find evidence and complementary data to support the claims. Table 2 provides a complete list of the observation sources for each of the participants.

Data were collected over the period from March 2015 to December 2015. All conducted interviews were transcribed verbatim and transcripts checked for accuracy. We

continued data collection until we judged that no new themes were identified and saturation was reached [24].

Table 4- Normalization Process Theory coding framework used for qualitative data analysis

	Differentiation	Enrolment	Skill-Set Workability Interactional Workability	Reconfiguration
Questions	What gets done in SM? What get done in other ways? What are the overlaps?	Can actors articulate the benefits of SM?	What do the users communicate through SM? To what extent does SM support co-productive work?	Do third party or charity organisations reflect on their activities on SM to develop new services through use of SM with co-production? Does reflection on SM contribute to redesign?
	Communal Specification	Activation	Contextual Integration Relational Integration	Communal Appraisal
Questions	How does SM contribute to the work? Do people agree with this as an account of the collaboration?	Can actors articulate how their work will change? Are they positive about this?	When users contribute in SM argument, does this have any influence on the decisions made? How does SM activity get captured and reused?	How does SM influence coordination between organisation and individuals in this context? Does SM let people build groups which are effective in service delivery?
	Individual Specification	Initiation	Interactional Workability Skill set Workability	Individual Appraisal
Questions	What does each actor use SM for? How is that different from what other actors do?	Do actors understand their new activities involving SM and are they happy to conduct them?	How do responsibilities change?	How do individual carers/service users appraise the effects of use of SM on them and their environment?
	Meaning (internalization)	Legitimation	Relational Integration Contextual Integration	Systematization
Questions	What would be lost if SM were not used?	To what extent do actors and organisations believe that the action involving SM are important to the provision of the service?	How does SM change the resource flow?	How do organisation (third sector or voluntarily) or individual users of SM in this context determine the effective (benefits or risks) or usefulness of SM in this context.

Data analysis

Data were coded in NVivo and thematically analysed for each type of SM. We drew on the four principles of co-production (equality, diversity, accessibility, and reciprocity) as a deductive coding framework, extracting excerpts from our qualitative data that had bearing upon how SM reshapes co-production. In addition, we also inductively identified emerging themes surrounding the benefits and challenges of SM in enabling

co-production in health and care, which served as an analytical lens to examine our data using a deductive approach to analysis [25]. Negative cases, i.e. those that did not fit within the narrative, were explored in the most detail.

Research Governance and Ethics

This study was granted ethical approval by University of Edinburgh, School of Informatics. Consent forms were signed and agreed with all participating respondents. Identities are protected and are assigned a confidential generic descriptor to ensure anonymity and all names changed.

Results

Our findings show that overall existing SM helps support the four principles that underpin co-production: equality, diversity, accessibility, and reciprocity and will influence the informal care sector to become more efficient. Below we explain how each principle of co-production can be enabled by existing SM. While appreciating the benefits we also found tensions caused by use of SM as well as challenges that inhibit use of SM for co-production.

Equality through sharing experience of users as valued assets

To enable equality, individuals need to have the same status within a group and the group needs to recognise the value of the contribution of all individuals. Some types of SM (in particular private Facebook Groups) seem to allow recognition of skills and abilities of all members within a group.

Private Facebook Groups (FBG) were widely used by people who wanted to be connected to each other in a secure and closed manner. Participation in these groups needed to be approved by the administrator(s) based on whether individuals are patients or carers of a person with a particular condition. Therefore, those who were members of these groups held experiences, skills, or abilities in dealing with the condition. This knowledge was recognised by others as an asset that could be shared leading to a sense of being valued by others.

"My knowledge is useful for others and their experience is valuable for me. We talk about our condition and liaising with each other and find ways to deal with issues…one particular case was when I had an issue in using my glucose meter and I found I was doing it wrong, I could've waited to see my GP, but got the answer in the group" (Patient and Carer)

These experiences and skills either facilitated knowledge exchange or provided mental support, which in either case were seen as important to the group members. There are clear considerations of empowerment when people feel that their knowledge and skills are contributing to a change in the world. Whilst many positive consequences exist, we also need to be aware of the issues that may arise from this knowledge sharing and empowerment. These issues include the extent to which knowledge leads on to changes in the productivity of the health and care system (and possible lack of applicability of knowledge for some members of the group), and the means to prevent inaccurate or harmful information from propagating through the network. In similar terms, health and care professionals express concern over the unregulated transfer of experience through SM, which leads to a need for filtering and integration of information in such groups.

In many cases the administrators of the groups also had the same condition as other members (or were carers of people with the same condition). Having the condition meant that they were also equally concerned about the surrounding issues and had dealt with them for a considerable time. Thus, on one had they brought comparable assets to the group and on the other hand, they were equal in terms of status and position.

"with a closed group, you could have a moderator or an admin who works with that condition, so... they are going to actually facilitate the whole group, and without their, service provision, that group wouldn't exist, and often the closed groups are not run by charities, they might just have been set up originally by someone who has had that particular experience, and they feel that there is a community for them of people in their situation out there, so they set it up themselves" (Patient)

As a result, whilst the member of these groups appreciated the equality of status, a new tension was created. Patients and carers acquired a considerable knowledge that could stand alongside health professionals; however, by no means were they equal in status or position to them. This in turn could lead to conflicts between the two groups.

This equality in terms of condition and experience removed the culture of "them and us" [26] This in turn, led to higher levels of support between all members (including administrators).

"they are volunteers who live with the condition, not employees of any organisation" (Patient)

This was achieved by closed-ness of the group (to ensure participants have similar levels of experience). However, this closed-ness could lead to tensions in terms of accessibility and diversity elements (discussed in the next section).

This equality in FBGs has empowered users to talk openly about their professional care practices and even discuss and find ways to approach professional carers (e.g. GPs, NHS consultants, etc.).

"I definitely feel more in control too. For example, I was fobbed off a couple of years ago when asking a doctor for vagifem and he said to use KY Jelly. The ladies here gave me the confidence to go back to my usual GP and ask assertively for the vagifem I knew I needed. He agreed that vagifem was a good idea and has prescribed it for me ever since." (Patient)

So in general FBGs (and forums) generated a sense of community which facilitated equality amongst its users. However, there were times that things didn't go as smoothly. Some members were aggressive about the stance they took on issues which could lead to disagreement, or in more extreme cases abandoning of the group.

"Some people are militant when talking about their stance pro/anti surgery for Colitis and Crohns. They'll really push their ideas on people and be very hard to talk to. You might have one person claiming to have the perfect solution to your problems: 'Just cut out dairy!' Or someone else claiming that surgery or medication is a con by the health professionals. With Colitis and Crohns there are such extremes of symptoms and illness and a lot of people are frequently misdiagnosed due to this." (Patient)

SM enables diversity by being inclusive of under-represented groups as well as by connecting diverse groups of people

Diversity was enabled by SM in two ways. Firstly, patients and carers are diverse in terms of characteristics (e.g. literacy) and conditions. These differences can lead to less ability to access and use resources. Inclusiveness means overcoming these diversities

and making sure that the people who are less likely to access/use resources are by some means gaining the benefit of this resources.

Patients mentioned that the closed nature of some SM in particular the private FBGs and forums gave them the ability to talk about issues which cannot be discussed face-to-face due to embarrassment about conditions of particular illnesses. This meant that some of those who were formerly excluded due to their conditions, could now benefit from these discussions.

"People are more open about their experiences because it's a closed group. They feel more open than if it was in the public domain…. Online support takes away a lot of the social difficulties of sharing in a group for fear of embarrassment or sounding stupid" (Patient)

"On a forum you talk about how you really feel, without any of the normal taboos. You can talk about anything." (Patient and Carer)

However, although this closeness of forums was an effective factor in facilitating some of these talks, it also created the challenge of getting into the groups. Thus, this closed-ness was a drawback as individuals could not join the groups without the permission of the administrators.

SM was not able to overcome many of the other barriers. For instance, interviewees highlighted that not everyone could have access to various SM types such as FBGs and forums. This could be due to limited internet access or low technological literacy.

Secondly, some types of SM, such as Twitter, acted as an effective place for connection of diverse people in health and care sector including professionals and non-professionals (carer and patients). In comparison to many other SM, Twitter was used by a larger number of professional people.

"I think generally Twitter has certainly helped us to increase the amount of people that we have on the network. And also, to increase the amount of people that come along to the events. But again, we feel that that's mostly in that professionals. So, we don't really think that it's been helpful in terms of targeting people with long term conditions or carers at the moment." (Organization Participant)

As twitter is a rapid and flat SM application, it provided a good space for users to find answers to their questions (without necessarily having to connect directly with people), getting current information and keeping up-to-date with health news.

"I think twitter been used for exchange of informal information and really really useful information around about research. I found it extremely useful for the work on health literacies …. So, you get to know people who are working and developing interesting stuff from health literacy … twitter is good for following and that keep yourself up to date." (Organization Participant)

The flat nature of Twitter (no connections needed) also provided a good platform for raising funds or promoting campaigns by organisations and charities. In doing so, organisations used Twitter to promote their activities and keep all users updated.

"so, we'd be very keen to promote our work [on Twitter], so we make sure that they're linked to, we would be promoting." (Organization Participant)

"it's useful for campaigns as well, so there's been a lot of really effective health campaigns on Twitter" (Organization Participant)

However, issues such as filtering imposed by the NHS in the use of SM on its premises, led to limitations in the use of such applications. One participant explained that their organisation set-up a blog, however its use was constrained due to the firewall introduced by NHS that blocked access to blogs during daytime for professionals.

"there are a massive [number of] health care staff using social media throughout our day but firewall is a big problem" (Organization Participant)

So, whilst SM enabled diversity in terms of opening up a space for communication and knowledge sharing of some patients (and carers) with particular conditions, as well as offering a fast and flat platform for various actors (including heath professionals, social workers and carers) to share news, there were yet many barriers that limited the use of SM. As highlighted by the participants, individuals who had Internet accessibility issues could be exuded from gaining the benefit from SM. This could be either due limited internet access or the inability of some elderly people in using technology.

SM makes groups' experience accessible

To allow accessibility means everyone should have the same opportunity to participate in activities in a suitable manner. By offering various types of platforms (e.g. blogs, FBGs, and Twitter), SM allowed different individuals to take part in knowledge sharing and communication in a way that suited them best.

"The one thing we found about Twitter, it seems to be very much used by the professionals. We find that most people with long term conditions and carers will use Facebook. Whereas with Twitter, we will seem to target lots of professionals." (Organization Participant) This allowed patients to gain access to some of the resources that were shared by professionals. Whilst helping them reach a new layer of information about particular conditions, this did not mean having direct access to knowledge that leveraged their own condition. Therefore, accessibility was enhanced to some extent and for some of the users.

Moreover, accessibility to group experience is enabled for those who have difficulty to gain access to others knowledge otherwise (such as through face-to-face meetings).

"I have quite a bad chest as you can hear, so I can be spending a lot of time on the forums or groups when I'm shut up in the house." (Patient)

This accessibility to knowledge from various sources, in turn, empowered users.

"I would say that social media certainly empowers you. By people sharing their experiences, it makes you far more informed. You can find out what kind of treatments are out there and go to appointments armed with information. I also felt more empowered in how I dealt with health professionals if I felt I wasn't being listened to. In fact, I later lodged a formal complaint to the health board." (Patient)

"I've just had my results in from my test". GP, I saw him two times, never once told me that these results' - and they were bad results- The GP missed it." (Organization Participant)

Whilst increasing patients' knowledge, this was not necessarily welcomed by all professionals. Some professionals preferred to guide patients' knowledge in certain directions. They believed that this knowledge is partial and it will either lead to loss of trust or 'interfere' with the course of their treatment (if patients take the advice from other sources rather than their direct health/care professionals). They also believed that this knowledge does not take account of other issues such as limitations in NHS funding. Therefore, it can lead to new conflicts in terms of accessing scarce resources.

Another difficulty mentioned by patients was excessive online accessibility. This referred to the fact that sometimes too much online activity could lead to reduced physical activity. In more extreme cases patients stated that too much focus on the negative comments of others could lead to discontentedness.

"Plus, you've got to watch that you don't get too immersed. You could easily spend all your time on Facebook, or on Forums." (Patient)
"And just talking to people about their illnesses might get you down". (Patient)
In order to reduce some of the negative effects of SM use, some organisations (such as charities) introduced content and structure 'configurations'. So, at the same time as giving a space to patients/carers to be active in sharing their stories, they would also put a control on what was shared and how it was shared.
"We're generally asking people about their story. And to share our story through our blog. So, we have like a set guideline for it. We will send people a guideline on how to write a blog, give them the word limit of the blog, and what kind of content it's good to have in a blog." (Organization Participant)
However, such controls were costly to manage as organisation members had to spend time going through each post and modifying them to meet the organisations pre-set framework. To manage this, some organisations used means of co-production by putting people with experience of effective post writings in touch with the newcomers to help them produce content, which was fit for purpose.

Reciprocity SM encourages reciprocity in sharing of knowledge and mental support

Reciprocity refers to the mutual process of giving and receiving something back. Users of SM, in particular FBGs and forums emphasised that they expected to gain something back from the group. Reciprocity may be direct (members behave in response to other members' acts) or indirect (cooperation with strangers to gain reputation) [27]. Direct reciprocity could be generally seen in offering knowledge and experience about a topic.
"Using social media is actually pretty empowering. When I was diagnosed, I had to become an expert on the condition and there's no better source of knowledge for this condition than your own lived experience. I did a lot of personal research: first asking doctors and nurses about it, but the best information comes from the women who live with it." (Patient and Group Administrator)
Indirect reciprocity, on the other hand, could be seen in offering mental support
"I wouldn't want to join a group unless I thought that people would be able to empathise and understand what I'm going through. There's no point in talking to people who don't understand- they won't respond appropriately." (Patient)
The sympathy that came from patients with similar health conditions (rather than paid organisational members) created added value for its recipients and led to the creation of a positive relationship.
"The knowledge and information comes from the members of the group. It's the people living with the condition who have the experience of self -managing, not paid employees of a charity who don't necessarily live with a condition." (Patient)
Both forms of reciprocity played an important role in keeping the communities going. Therefore, administrators encouraged members to participate in talks, to make sure that everyone is receiving something back from the group.
"we ask people to be active participants in the group: to commiserate with each other on a bad day, to be supportive of each other and share knowledge and experiences." (Patient and Group Administrator)
Some administrators went further by deleting the members who were not active for a certain period of time.
"People who don't participate for a more than a couple of months are deleted from the group." (Patient and Group Administrator)

However, lack of involvement in discussions was sometimes due to lack of knowledge in the topic area or disagreement with the stance taken by other individuals. Therefore, administration of groups was a challenge.

"Even if I don't comment on posts, I read them so that I may be aware of any issues I may face … I don't like the idea of taking HRT (Hormone Replacement Therapy) or any other things like creams and stuff- I prefer the natural route but I do understand now with information posted that each individual has their own opinions on the matter. These opinions and choices are personal to them and I take that on board now because this information is important knowledge." (Patient)

So whilst reciprocity was important in terms of the overall activities of individuals, the administrators needed to be considerate of members with lesser contributions. In some cases, some patients and carers started their participation as lurkers, just to get a feeling about the environment or to gain some specific knowledge. It would then take some time for them to reciprocate to the group. Therefore, user engagement could be seen as a gradual phased process. For those people with lower levels of engagement, who would be passive readers, it could begin by encouraging them to read more regularly, then starting to comment and then contributing. The use of SM creates the opportunity to allow for growth of continuous knowledge and emotional conversation of strangers.

Discussion

Summary of findings

This work indicates how different types of SM enable co-production by supporting its underlying principles: equality, diversity, reciprocity and accessibility. The paper also offers insights into the challenges involved in use of these SM as an enabler of co-production. Individual users (patients and carers) and organizations providing health care services to elderly people, adopted various kinds of SM to meet their diverse needs. We observed that people's contributions evolved as they became more experienced in the use of SM. Table 5 summarises the benefits of each type of SM in terms of co-production principles.

In general, private FBGs were the most widely used SM by patients with similar conditions and their carers due to their greatest offerings around 1) equality of members and valuing their experiences as assets; 2) diversity and inclusion of members whose voices are less heard otherwise; 2) accessibility for people from different geographical locations; and 4) reciprocity of knowledge sharing and mutual support. Forums were similar in terms of benefits and use, however they were mainly sponsored (and administered) by organisations. This allowed for better control of data, however their formation and access were more challenging. Microblogging (e.g. Twitter) was also seen as one of the most highly used SM applications which plays very important role in health and care by both professionals (e.g. doctors) and non-professionals (patients). Its 'flat' nature allowed rapid exchange of information based on users interest in topics. Therefore, patients needing information or updates about particular diseases could easily gain access to information shared by health and care professionals. It was also highly used by those who wished to attract communities of interest or funds or those who wanted to provide/receive fast update about news and various topics. Therefore, it served for a very different purpose to those of FBGs and forums. Blogging, on the other hand, was used for slow but detailed sharing of stories by people and organisations about their health interests and experiences. We found four affordances

of SM that supported care for elderly people: knowledge creation and sharing, information dissemination, emotional support, new communication channels. SM afford behaviours that were difficult (or impossible) to achieve before these new tools were used by those involved in the care of elderly people. We further found mechanisms that affect how people engage in the knowledge and support conversation, which may have positive effects or may result in adverse consequences not intended by the participants or other groups involved in care of elderly people. These emergent tensions are the basis for the implications we draw.

Table 5- SM for co-production

	Equality	Diversity	Accessibility	Reciprocity
FBGs	Patients with same condition and their carers; Experience and skills seen as asset	Less heard voices are included	Members from diverse geographical locations	Mutual support; knowledge sharing; administration of participation
Forums	Patients with same condition and their carers; Experience and skills seen as asset	Less heard voices are included	Members from diverse geographical locations	Mutual support; knowledge sharing; administration of participation
Micro-blogging		Professionals and non-professionals; No direct connections needed	Re-tweets; provides access to another SM	
Blogging			Accessible by all	Feedback on blogs

In this way, SM offered new modes of communications between not only patients and their carers, but also between them and the professionals. On one hand, professionals gained access to patient stories (blogs, FBGs and Forums) and the details of conditions. This information can be used by doctors for better diagnosis and monitoring of particular patients. On the other hand, patients and carers gained access to new healthcare findings.
Also, the joint effort in creation of and monitoring of knowledge contents as well as the self-promoting nature of SM improved the productivity of health and care organisations by enabling them to publicise information using low cost mediums.

Interpreting findings in the context of the wider literature

The large body of extant studies around the use of SM for healthcare focus on who uses these tools [17, 28-31] and uses of SM for communication [11, 32-34]. The studies show that SM increases patients' and carers' access to health information [14, 35-44]. Whilst our study confirms this, we specifically show that SM makes various types of health and care resources visible to meet the needs of elderly patients. These resources include availability of carers (including professional and non-professional resources), care programmes (e.g. outgoings, charity programs, and etc.), knowledge about symptoms and cures of different conditions (including diets and drugs), new communication techniques with professionals, and more. We show that by facilitating new modes of dialogue between different actors (i.e. patient-patient, patient-carer, carer-carer, and patient-professionals, patient-health/care organisation), SM enables new, faster and

more effective modes of social interactions in which patients become empowered by having access to more resources.

SM offers a wide range of benefits for health communication which can be grouped into increased interaction around general [17, 45] and sensitive information [13], better accessibility of information [17, 32, 33, 44, 46-52], and emotional support [10, 13, 40, 53-61]. We use Cohn's co-production framework to expand the extant findings by showing how such characteristics act as the key principles of co-production. Our work shows that SM enables recognition of the experiences and skill of all participants as assets, and enables them to engage with the community and become active. Our study also expands the existing literature, by showing that the fulfilling of different needs by various SM is influenced by different factors including the speed of knowledge creation and dissemination, the speed of feedback and discussions, the detailed nature of knowledge exchanges, the type of discussion (support versus news versus health knowledge sharing), and the openness and closed-ness of activities. These characteristics help better co-ordination and communication of knowledge resources between carers and patients.

There are also limitations in use of SM. Information quality concerns and the lack of reliability of the health information [10, 38, 40, 41, 45, 53, 62-69] are amongst the widely discussed limitations. Whilst our findings confirm these, we also show that the explication of common resources may lead to new forms of competition and conflicts. In particular, the new knowledge that is obtained by users is not always welcomed by professionals. This could be due to numerous reasons, including lack of validity of all information obtained as well as higher demand for treatments as they become known to patients and carers. Also, due to concerns about information quality and validity, some healthcare organisations need to put into place new forms of information monitoring which may be costly.

Strengths and limitations

This paper has a number of strengths and limitations. We drew on NPT [23, 70] which served as a socio-technical analytical lens to help us analyse the benefits as well as challenges of various types of SM. We have drawn data from multiple different sources including patients, carers, charity organisations to enhance confidence in our findings and included diverse perspectives. However, due to the sensitivity of patient data, we only had limited access to private FBGs and Forums. We overcame this problem by contacting many groups and gaining access to one particular group. To also understand other groups that were important for this research, instead of observations, we interviewed its users. We also did not seek the perspective of NHS professionals including doctors. This can be addressed in future research with a focus on professionals. Finally, in this paper we have focused on communication and cooperative utilization of health and care resources. Therefore, further research is needed to focus on resourcing, conflict and competition for resource, and the overall governance of health and care provision.

Conclusion

SM has gained momentum within the health and care community by: offering significant benefits for patients, carers and even professionals; increasing interaction; providing more readily available and customised information; offering mental support; promoting health and care related activities; offering a platform for communication for under-

represented individuals; allowing reciprocal sharing; and enhancing the communication between patients, carers, and professionals. All these benefits have the potential to be realised through SM. These benefits facilitate co-production by enhancing equality, diversity, accessibility and reciprocity, and lead to recognition of resources (skills and time), joint creation and monitoring of knowledge, and direct and indirect mutual support. This in turn can lead to resource savings needed to manage the growth in demand from the expanding elderly population. SM allows users to learn from each other (in a less costly manner) and can facilitate communication more effectively (in particular professionals and non-professionals).
However, despite these benefits in facilitating co-production, existing SM does not fully enable co-production. There are as yet outstanding issues in arranging the common pool of health and care resources to better enable co-production. Different SM enable co-production (co-delivery) of services for elderly people to varying extents. In particular SM is used distinctly differently by professionals and non-professionals. This can be seen as an opportunity to leverage their benefits in a more productive manner.

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Abbreviations
SM: Social Media
FBG: Facebook Group
NPT: Normalization Process Theory
NEF: New Economics Foundation
ICT: Information and Communication Technology
CPR: Common Pool Resources

Competing interests
All authors declare that they have no competing interests.

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